

**ASSESSING BEHAVIORAL CHANGE IN RESPONSE TO FAMILY HEALTH
HISTORIES**

by

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The Center for Minority Health (CMH), located in the University of Pittsburgh's Graduate School of Public Health, was established to promote health and prevent disease. Its mission is to eliminate racial and ethnic health disparities in Pittsburgh by the year 2010. The Healthy Black Family Project (HBFP) was one project designed to meet this goal by reducing the prevalence of diabetes and hypertension in Pittsburgh. The Family Health History Initiative is one part of HBFP; its purpose is to educate participants about the importance of family health history as a risk factor for disease. By providing personalized risk assessments based on family history, genetic counseling students at the University of Pittsburgh hope to encourage individuals to adopt healthy lifestyle behaviors in an effort to reduce their risk for multifactorial conditions like cancer, heart disease, hypertension, and diabetes. This project was designed to assess the ability of a family health history session to encourage participants to increase their physical activity. Using the transtheoretical model, information about the physical activity habits of participants before and after a family health history session was collected. This data was analyzed to determine whether or not individuals increased their physical activity after a family health history session; data collected from individuals who had completed a Health Risk Assessment but not a family health history session was compared. The data show that individuals who complete a family health history session are more likely to increase their physical activity than individuals who complete a Health Risk Assessment. Most individuals who completed a family

health history session, however, did not progress along the stages of change, defined as precontemplation, contemplation, preparation, action, and maintenance. Individuals who earned less than \$20,000 a year, who perceived themselves to be obese, who intended to increase their physical activity, who had a moderate risk for any disease, and who perceived themselves to be at high risk or reported already having a disease were more likely to improve along the stages of change than other individuals. This study provides public health significance by defining the effectiveness of a family health history as an intervention.

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1.0 INTRODUCTION

This research was conducted through the Center for Minority Health in the University of Pittsburgh's Graduate School of Public Health. The Center for Minority Health was established in 1994 and has been directed by Dr. Stephen Thomas since 2000. Its mission reflects the goals of Healthy People 2010: the elimination of racial and ethnic health disparities by the year 2010. The Center for Minority Health has established seven priority areas, which include: cancer screening and management, cardiovascular disease, diabetes, HIV infection and AIDS, immunizations, infant mortality, and mental health. In order to address these disparities, the Center for Minority Health designs programs that promote health and prevent disease. One such program is the Healthy Black Family Project, which aims to reduce the prevalence of hypertension and diabetes in the East End of Pittsburgh. The Family Health History Initiative is one part of the Healthy Black Family Project; its purpose is relay the importance of family health history as a risk factor for disease and to provide personalized risk assessments for individuals based on their family health histories. The hope is that such information will encourage individuals to make positive lifestyle changes, including increased physical activity, improved diet, increased health screening, and smoking cessation. The following literature review provides a basis for this research, including an overview of racial and ethnic health disparities, the importance of family health history, and the ability of the transtheoretical model to assess lifestyle changes that occur as a result of an intervention.

HEALTH DISPARITIES IN THE US

African Americans comprise approximately 12% of the US population (1), but they bear a disproportionate burden of chronic disease that results in higher morbidity and mortality and leads to a shortened life expectancy. The increased prevalence of many health conditions in the African American population begins with an increased prevalence of risk factors for certain diseases. For instance, more African American children and adults are considered overweight or obese than other racial groups. Overweight and obesity are strong risk factors for heart disease, diabetes, and cancer. In the United States, 61% of adults are considered overweight ($BMI \geq 25$) and 30% are considered obese ($BMI \geq 30$), but 40% of African American adults fall into one of these categories, whereas only 29% of Caucasians do (2,3). Similarly, 22% of African American children aged 6-19 are considered overweight or obese while 12% of Caucasians in this age range are (3). The situation is worse for African American women than their male counterparts. Seventy-seven percent of black women are overweight and 49% are obese, while 57% of Caucasian women are overweight and 31% are obese (2). African American adults are also less likely than Caucasians to engage in regular physical activity, another important risk factor for chronic disease. While 35% of Caucasian adults report regular moderate physical activity, only 25% of African Americans report the same (3,4).

In 2002, the three leading causes of death for both blacks and whites in the US were heart disease, cancer, and stroke. Diabetes, the fourth leading cause of death in African Americans, is the eighth leading cause of death for Caucasians (3). Each of these four health conditions affects African Americans more seriously than Caucasians. African Americans are more likely to die from heart disease at a young age than other racial groups. In the black population, 31.5% of the deaths due to heart disease occur prematurely (in individuals under the age of 65)

compared to premature death rates of 16.8% in the general population and 14.7% in Caucasians (5). Cardiovascular disease accounts for one-third of the disparity in potential life-years lost between African Americans and Caucasians, making it the largest contributor to mortality disparities (6). Hypertension, a risk factor for heart disease, accounts for almost half (15%) of the cardiovascular disparities (6). The occurrence of hypertension is disproportionately high in the black population; the incidence of hypertension in African American females is 39.4 per 100,000, whereas the incidence for white women is 23.3 per 100,000. Similarly, the incidence in black men is 36.8 per 100,000, but in Caucasian men is 23.9 per 100,000 (3).

Adult-onset diabetes is another large factor in the difference between African American and Caucasian mortality, comprising 8.5% of the disparity (6). Overall, complications from diabetes result in three times more potential life-years lost for blacks than whites (3). Individuals with diabetes are also more likely to develop cardiovascular disease; the fact that African Americans have increased prevalence of diabetes may contribute to their higher risk of heart disease as well (5). African Americans also have three times as many potential life-years lost as a result of stroke (3).

Cancer also affects African Americans at higher rates than expected. Blacks in the US have the highest combined cancer mortality rate and also have the highest mortality rates for most major types of cancer (2). Black men are 20% more likely to develop cancer than white men and 40% more likely to die from cancer. Black men are 60% more likely to develop prostate cancer and are 2.4 times more likely to die from prostate cancer than white men (2). Black women have a 20% higher mortality rate than white women despite the fact that they are 10% less likely to develop cancer than white women. They have a 60% higher incidence of uterine/cervical cancer and are 2.2 times as likely to die from it. Although African American

women are 20% less likely to develop breast cancer than white women, they have a 30% higher mortality rate due to breast cancer. Black women are also 30% less likely to develop ovarian cancer but are 20% more likely to die from it (2). African American males and females have higher incidence and mortality rates for many other types of cancer, including myelomas, stomach cancer, and colorectal cancer. African Americans are typically diagnosed at a later stage of cancer than whites, which contributes to the higher mortality rates they experience (2). Overall, the five-year survival rate for African Americans is 56%, while it is 66% for Caucasians (7).

African Americans in Allegheny County face similar health disparities as those across the country. They are twice as likely to die from diabetes as white citizens in Allegheny County. African Americans between the ages of 65 and 74 in Allegheny County are also 1.5 times as likely to die from stroke as their white counterparts. Black women between the ages of 44 and 54 are three times as likely to die from cardiovascular disease. Black men between the ages of 34 and 44 are also three times as likely to die from cardiovascular disease; black men between the ages of 65 and 74 three times more likely to die from prostate cancer than white men (8).

As a result of the health disparities they face, in combination with other factors, African Americans have a shortened life span compared to Caucasians. In 1999, the average American's life expectancy was 76.9 years, whereas the average African American's life expectancy was only 71.4 years (1). In 2001, Caucasian males lived an average of 75.0 years while black men had a life expectancy of 68.6 years (2). This disparity in life expectancy also exists for women. African American women had a life expectancy of 75.5 years, whereas white women had a life expectancy of 80.2 (2). In Allegheny County, the disparities in life expectancy African Americans face parallel the national statistics. In 2002, black males lived an average of 5.7 years

less than white males and 10.8 years less than white women; black women lived an average of 3.0 years less than white women (8).

The causes for the health disparities that African Americans face are diverse and not completely understood. Three contributing factors to these disparities are socioeconomic status (SES), poor access to health care, and racial discrimination. SES is comprised of several components, including income, education level, occupational prestige, and employment status; African Americans fare worse than whites in each of these categories. Although 13% of the total US population lives below the poverty line, 24% of African Americans are considered poor (2). African Americans are more likely than whites to experience poverty at all ages; they also have lower education levels and higher unemployment rates than whites, which contribute to poverty and SES (9). Poverty influences many aspects of life that contribute to a person's health. Individuals living in poverty are more likely to live in dangerous housing and have poor nutrition and they have an increased prevalence of tobacco use and obesity (7,10).

Although SES contributes to the health disparities experienced by African Americans, it cannot fully explain them. Howard et al. found that SES can account for disparities in mortality due to diabetes and heart disease in black females and stroke and lung cancer in all African Americans, but cannot explain the higher African American mortality rates for stomach cancer in women, pulmonary disease, prostate cancer, and hypertension (11). A study by Nazroo supports these findings by reporting that income differences between blacks and whites can account for only two-thirds of mortality disparities (12).

African Americans also have poorer access to health care than Caucasians. To some extent, this difference is the result of lack of health insurance coverage in the African American population. While 87% of Caucasians under the age of 65 have health insurance, only 81% of

African Americans do (3). Even with insurance coverage, cost may be a barrier to care for African Americans. According to the 1997 Behavioral Risk Factor Surveillance Survey (BRFSS) conducted by the CDC, blacks are more likely to report poor access to health care as a result of both lack of insurance and prohibitive costs (4). Even when African Americans do have access to health care, it is not as likely to be high-quality health care. African Americans are more likely to live in rural or inner-city areas that do not provide access to quality health care (7). An article by Bach et al. reported that black Medicare beneficiaries are more likely than their white counterparts to see doctors who are not board certified and who report that they are unable to provide high-quality health care to their patients (13). Examples of poorer quality health care that African Americans face include less preventive medicine, fewer early detection methods, lower quality treatment options, and less access to high-quality sub-specialists and diagnostic imaging and non-emergency admission to the hospital (7,12).

Lack of access to quality healthcare is in part due to racial discrimination. In 2003, Freeman reports that African Americans are less likely to receive curative surgery for early-stage lung cancer, are less likely to be referred for renal transplantation, and are less likely to be treated with pain relievers for long bone fractures. He also points out that the effects of race can influence the patient's willingness to engage in health-promoting acts; an African American patient may be less likely to trust a doctor of another race and may also be less likely to participate in potentially beneficial clinical trials (14). Racial discrimination also affects health through psychological factors. Nazroo reports on several studies that have shown a relationship between racial discrimination and hypertension, psychological distress, poorer self-rated health, and the number of days spent unwell in bed (12). African Americans are also more likely to report poor health status than whites in the BRFSS (4).

THE IMPORTANCE OF FAMILY HEALTH HISTORY

Many of the health disparities that African Americans face stem from common multifactorial conditions like heart disease, cancer, and diabetes. Multifactorial conditions are so named because they are the result of many different components. Unlike single-gene disorders that follow simple patterns of inheritance, these conditions arise from complex combinations of gene-gene and gene-environment interactions. The development of heart disease, cancer, and diabetes are influenced by many different genes that work together to either predispose or protect an individual. Likewise, an individual's likelihood of developing one of these conditions is influenced by the interaction of these genes with that person's environment. Factors such as smoking, diet, and physical activity can affect the probability of developing a multifactorial disease. Multifactorial conditions therefore tend to run in families, but are not inherited in a clear, linear fashion; instead, individuals with a family history of a multifactorial condition tend to inherit a predisposition to that condition. That predisposition can be encouraged or discouraged to develop based on an individual's environment. A family health history, or pedigree, is therefore a useful way to predict an individual's risk for a multifactorial condition because families share not only genes, but also environments and behaviors.

If an individual has a family history of a multifactorial disease, he or she is at an increased risk for that condition. Broadly, studies have reported that a positive family history of a common chronic disease is associated with a risk 2 to 5 times greater than the general population risk (15). Multiple studies on type II diabetes have shown that a family history of the disease leads to a two-fold to six-fold increased risk (16). Some studies have found a higher risk associated with a maternal, rather than paternal, history of diabetes, but not all studies have confirmed these findings. Numerous studies have reported a higher risk of diabetes if both

parents are affected as opposed to just one (16). Erasmus et al. compared diabetic and non-diabetic black South Africans and found a correlation between family history and diabetic status. Of 1,111 participants with type II diabetes, 27.3% had a positive family history, compared to a rate of 8.4% in a group of 687 non-diabetic controls (17). This study also found that individuals are more likely to develop diabetes if their mothers had the disease than if their fathers were affected; 67.4% of diabetic participants had a diabetic mother, while only 27% of patients had a diabetic father (17). Erasmus et al. also concluded that diabetics with a positive family history developed the condition earlier than patients without a family history of diabetes. The mean age of onset for diabetics with a family history was 44.7 years, whereas the mean age of onset for participants without a family history was 51.5 (17).

Family history can also be used to predict risk for heart disease, especially premature coronary heart disease (CHD) occurring in individuals under the age of 55. In the Healthy Family Tree Study in Utah, 14% of families had a positive family history of CHD, but they accounted for 72% of premature CHD events and 48% of total CHD events (18). Other studies have also shown an increased risk in cardiovascular disease for individuals with a positive family history. The Western Collaborative Group found that individuals with parental history of CHD are twice as likely to experience heart attack and angina as individuals with no family history of heart disease (19). Another study, the Rancho Bernardo California Study found that men under the age of 60 with a family history of heart attack were 5 times as likely to die from cardiovascular disease and CHD (19). The risk of heart disease increases with the number of affected relatives, but studies have reported conflicting results about whether maternal versus paternal family history more heavily influences an individual's risk for CHD (19).

Because family history is an accurate predictor of risk for different multifactorial conditions, public health organizations have considered using it as a population based screening tool to identify at-risk individuals. In order to be an effective screening tool, a family history must be able to identify at-risk individuals, improve early detection and disease prevention, and promote healthy behaviors (19). To achieve these goals, the tool must have analytical and clinical validity, as well as clinical utility. Analytical validity addresses how effectively a family history identifies disease among family members. It consists of both sensitivity—the correct identification of family members with disease—and specificity—the correct identification of family members without disease. Clinical validity refers to the ability of a family history to accurately predict disease risk. Clinical utility assesses whether or not a family history tool can effect behavior change aimed at preventing disease (19). Many studies have been performed to assess these measures; unfortunately, most of the studies either do not report their racial composition or have a low percentage of African American participants.

Several studies have indicated that self-reported family histories are accurate, suggesting that a family history tool would have strong analytical validity. A study comparing Hispanic and non-Hispanic whites by Kahn et al. that assessed the validity of self-reported family history of diabetes reported complete agreement between the diabetic status as reported by probands and by the reportedly affected relatives (20). Kee et al. reported 67.3% sensitivity and 96.5% specificity for a study investigating self-reported family history of heart attack in first-degree relatives (20). The Healthy Family Tree Study in Utah by Hunt et al. found that reports of family history of CHD had 79% sensitivity and 91% specificity (19). Love et al. reported that participants correctly identified family members' cancer status and site in 91% of breast cancer cases and 89% of colon cancer cases (20).

Research has also confirmed the clinical validity of a family history tool. Other authors have repeatedly cited the 1997 paper by Scheuner et al. as an accurate predictor of risk based on family history analysis (1,4,12). The study consisted of 200 couples in a prenatal setting; 6% of the study population was African American. Scheuner et al. created a risk stratification system for individuals based on their family histories of heart disease, stroke, hypertension, type II diabetes, and breast, ovarian, endometrial, colon, and prostate cancers; the study participants were classified as average (general population), moderate, and high risk based on their family histories. If an individual has no affected family members or has only one affected second-degree relative, he or she is considered to have an average risk for that disease. A positive family history, indicating an increased risk for disease, consists of having at least one affected first-degree relative or two affected second-degree relatives from the same side of the family (20). The results obtained from using this risk assessment tool corresponded to previously reported results and estimates of familial disease prevalences. Using their tool, Scheuner et al. reported that 29% of individuals were at risk for heart disease and 14% of individuals were at risk for type II diabetes (20). Overall, 5-15% of participants were at moderate risk for one of the studied conditions and 1-10% of individuals were at high risk for one of the diseases (20).

In order for a family history tool to have clinical utility, it must be effective in encouraging behavior that will reduce risk and prevent disease. Studies investigating the effect of family history on behavior have reported the most success if participants have accurate risk perception. Some studies indicate that many individuals with a family history of disease do not have accurate risk perceptions. One study by Pierce et al. reported that individuals who have a parent with type II diabetes are aware that they have an increased risk, but that they underestimate that risk and do not know how to reduce their risk and prevent disease (16). In a

review of several studies, Harrison et al. concluded that less than 40% of individuals with a positive family history of diabetes perceive themselves to have an increased risk of developing diabetes and that those who do perceive themselves to be at increased risk still underestimate their risk (16). These misperceptions may arise from a lack of complete family history knowledge. A CDC report on the 2004 HealthStyles Survey (n=4,345; 11.5% African American) indicated that although 96.3% of respondents believe that knowledge of family history is important in maintaining good health, only 29.8% of those individuals had actively collected information about their own family histories (21).

Other studies have indicated that individuals with a family history of disease are aware of their increased risk and that they modify their behavior accordingly. Forsyth et al. reported that individuals with a parental history of diabetes perceive themselves to be at higher risk for diabetes and that they report more frequent protective behaviors, including weight reduction, diet, exercise, and regular visits to their doctors (16). A survey by the Montana Department of Public Health revealed that respondents with a positive family history of diabetes were more likely to have been screened for diabetes in the past year than respondents without a family history (22). In 2000, Hunt et al. reported that individuals with a family history of heart disease who perceive themselves to be at increased risk for developing heart disease are less likely to smoke than other individuals (23). Individuals with a family history of cancer are also more likely to engage in protective health behaviors as well. Women with a family history of breast cancer are more likely to have screening than women without a family history (24). Similarly, individuals with a family history of colon cancer are more likely to have colonoscopies than other individuals (25).

The results of these studies indicate that if a family history tool can improve an individual's risk perception, he or she will be more likely to engage in risk reducing, disease prevention behaviors, including increased screening, improved diet, and increased physical activity. Each of these measures is effective in preventing disease. For example, the Finnish Diabetes Prevention Study reported that individuals who received lifestyle interventions had a 58% lower incidence of diabetes than a control group (16). Khoury suggests using a tool that stratifies risk based on the number of family members affected, the degree of relatedness, and the age of onset (26). Scheuner et al.'s tool fulfills these components and classifies individuals as average, moderate, or high risk. Individuals at average risk for disease based on family history can be encouraged to follow the standard public health prevention recommendations. If individuals are classified as being at moderate-risk, they have personalized prevention recommendations. High-risk individuals should also have personalized recommendations; they may also benefit from genetic counseling for single-gene syndromes (26).

THE TRANSTHEORETICAL MODEL

In order to be an effective tool in reducing the health disparities between African Americans and Caucasians in the US, a family health history intervention should be able to encourage positive health behavior changes. Regular physical activity is a behavior helpful in preventing many of the multifactorial conditions that account for health disparities. The ability of a family health history session to encourage increased physical activity, then, is an important measure to assess.

Several studies have successfully used James Prochaska and Carlo DiClemente's transtheoretical model to quantify changes in physical activity over time. The transtheoretical

model is based on the idea that people move through stages while making the decision to engage in behavior change. Prochaska and DiClemente outlined five stages of change: precontemplation, contemplation, preparation, action, and maintenance (27). Individuals in the precontemplation stage do not intend to make any behavior changes, usually because they do not recognize a problem with their behavior. If asked about their behavior, these individuals may respond that they do not intend to make any changes in the next six months. The contemplation stage is characterized by acknowledgement of a problem and a desire to change behavior. Contemplators are considering changing their behavior but have not yet committed to a change; they may respond that they intend to make a change within the next six months if asked about their habits. The next stage of change is preparation, which is characterized by a commitment to making change. Individuals in this stage report the intention to make behavior changes in the next 30 days; they may have already begun to make small changes leading up to their definitive action. Action is the stage at which individuals modify their behaviors; individuals in this stage report that they have successfully changed their behavior for less than six months. The last stage in the transtheoretical model is maintenance; individuals in this stage have been successful in effecting behavior change for more than six months. An important component of these stages is that progression through them is not linear; individuals at any stage can relapse to previous stages.

The model was originally applied to the cessation of addictive behaviors such as smoking and drug or alcohol abuse. It has since been used with the adoption of positive behaviors such as physical activity as well; most of the published studies do not report their racial composition, so the applicability to African Americans is difficult to estimate. In 1993, Marcus and Simkin published the results of a study in which they applied the stages of change to exercise habits

(28). They classified subjects into each of the five stages using standard stages of change questions. The subjects' answers were compared to their self-reported amount of physical activity as assessed by the 7-day Physical Activity Recall questionnaire. Individuals in the maintenance and action stages engaged in significantly more physical activity than those in the precontemplation and contemplation stages. Marcus and Simkin thus concluded that the stages of change questions were an accurate method of assessing the level of physical activity. In the years since this study, many others have validated the use of the transtheoretical model in the realm of physical activity. Wyse et al. performed a similar study in British young adults; their analysis revealed significant differences in self-reported levels of exercise between individuals in the precontemplation/contemplation, preparation, and action/maintenance stages (29). In 2001, Marshall and Biddle published a meta-analysis of studies that had researched the validity of the transtheoretical model's application to physical activity. They reviewed data from 71 studies and found that overall, the level of physical activity increased as individuals moved up the stages of change. They noted that the largest change occurred between the preparation and action changes, as would be expected since that movement indicates the time at which individuals begin to meet the requirements for physical activity. Marshall and Biddle concluded that these studies provided sufficient data to confirm that each stage is associated with a different level of physical activity (30).

Research from Richards Reed et al. has further honed the application of the transtheoretical model to physical activity habits (31). They recommend using a comprehensive well-defined description of physical activity to ensure more accurate and consistent responses. They also suggest assessing participants' stages by asking if they meet the definition and providing five answer choices: "Yes, I have been for more than 6 months;" "Yes, I have been for

less than 6 months;” “No, but I am planning to start in the next 30 days;” “No, but I am planning to start in the next 6 months;” and “No, and I don’t plan to start in the next 6 months.” Richards Reed et al. report that these methods of collecting data garner the most valid and reliable results.

Assessing whether or not an intervention is successful in changing physical activity behavior using the transtheoretical model appears to be feasible. Kirk et al. designed an intervention to increase physical activity in people with type 2 diabetes and measured its success using stages of change (32). Before the intervention, all of the participants and controls were in contemplation or preparation stages. Twelve months into the study, they reassessed the participants’ stages of change. Eighty-five percent of the controls were still in contemplation or preparation, whereas 61% of the experimental group had moved into action or maintenance. The intervention, therefore, proved to be successful and the transtheoretical model was a useful tool to measure the results. Many other studies have also investigated the usefulness of the transtheoretical model in effecting behavior change. In 2003, Adams and White published a critical review evaluating the effectiveness of physical activity interventions based on the transtheoretical model. This review included data from 26 publications; the programs described in these papers staged people based on their physical activity intentions or actions and then provided stage-specific interventions to increase physical activity. Adams and White found that 11 of 15 programs (73%) reported short-term significant improvement in stage progression and physical activity levels. Two of the seven programs (29%) that investigated long-term effects (more than six months) of the interventions reported some benefit. Adams and White thus concluded that interventions based on the transtheoretical model are effective for in the short-term; they also report that data on long-term benefits is limited, but currently disappointing (33). Based on prior research, then, using stages of change questions before and shortly after a family

health history session may prove to be a successful way of assessing whether or not it is an effective intervention.

2.0 METHODS AND PROCEDURES

HEALTHY BLACK FAMILY PROJECT

The HBFP is a program designed by the Center for Minority Health to promote health and prevent disease. Its specific aim is to reduce the prevalence of hypertension and diabetes in the African American community of Pittsburgh. HBFP is centered in a geographic area entitled the Health Empowerment Zone; this area consists of East End neighborhoods and includes East Hills, East Liberty, Homewood North, Homewood South, Homewood West, Larimer, Lincoln Larimer, and Wilksburg. (See figure 1). Seventy nine percent of the citizens in these communities are African American and 25.7% of the East End population lives below the poverty line. HBFP was designed to engage these communities in an effort to improve the health of its citizens.

Zip Code	Neighborhood
15147	Penn Hills
15206	Lincoln, Lemington, Belmar, East Liberty, Larimer, Garfield
15207	Glen Hills
15208	Point Breeze North, Homewood South, Homewood North, Homewood West
15213	Terrace Village, Upper Hill
15219	Crawford Roberts, Terrace Village, Middle Hill, Bedford Dwellings, Upper Hill
15221	Homewood North, East Hills, Wilkinsburg
15224	Garfield

Figure 1. Health Empowerment Zone

FAMILY HEALTH HISTORY INITIATIVE

The Family Health History Initiative is one part of HBFP. It was designed to educate HBFP participants about the role of family history as a risk factor for disease. Genetic counseling students in the Graduate School of Public Health at the University of Pittsburgh go into the communities within in the Health Empowerment Zone and participate in community events, such as HBFP orientation sessions, church gatherings, and health fairs. During these events, the counseling students discuss the importance of family health history knowledge with attendees and interested individuals can sign up for a family health history session with one of the students.

The students call these individuals and establish a time and location to meet for the family health history session. During the session, participants relay the information they have about their family's health history and the counseling student draws a pedigree. After the pedigree is complete, the student provides a risk assessment for common health conditions like heart disease, hypertension, diabetes, cancer, and Alzheimer's disease and for any other health conditions that are in the participant's family history. At the conclusion of the session, the participant receives a copy of the hand-drawn pedigree. If the participant so requests, the counseling student creates a computer-generated copy of the pedigree using Progeny® software. The student then mails this copy along with targeted health information and a certificate of appreciation to the participant.

MINORITY RESEARCH RECRUITMENT DATABASE

During the family health history session, participants have the opportunity to enroll in the Minority Research Recruitment Database. This database was designed to increase minority participation in research, as minorities are historically underrepresented in clinical trials. At the end of the family health history session, the counseling student explains the concept of the database and participants are given the option of enrolling by providing written informed consent. If participants consent, their pedigrees are stored in Progeny®. When the Center for Minority Health obtains information about a clinical trial, the counseling students search the database for individuals who might qualify for the study based on their personal or family histories. They then generate a letter with the information detailing the study and mail it to the appropriate individuals.

ASSESSING AFRICAN AMERICAN'S RESPONSE TO FAMILY HEALTH HISTORIES

This study's purpose was to assess African American's response to family health histories. This study was funded by a grant to Stephen B. Thomas from the National Institutes of Health: National Center on Minority Health and Health Disparities EXPORT Grant II, and received approval by the University of Pittsburgh's Institutional Review Board (IRB) in May 2004, with subsequent renewal in April 2005 and modification in July 2005. (See Appendix B). The specific aims of the study were: 1. To determine how knowledge of family health history influences the accuracy of individual risk perception; 2. To determine how knowledge of family health history shapes the willingness of African Americans to participate in clinical research studies; 3. To determine how knowledge of family health history influences "information seeking" behavior; and 4. To determine how the process of completing a family health history affects and individual's level of physical activity. The first two aims of this study were investigated in the master's theses of two former genetic counseling students. This thesis will focus on the fourth specific aim of the study.

PROCEDURE

All individuals who completed a family health history session were given the opportunity to participate in this study. At the beginning of the session, the counseling students explained that in addition to creating the pedigree, individuals had the option of completing two brief surveys before and after the family history was drawn. If participants expressed interest, the counseling students reviewed the informed consent, including the specific aims, process, risks, and benefits

of the study. The participants then provided written consent and completed the pre-survey, which consisted of questions about demographic information, risk perception, and physical activity habits. (See Appendix C). Once the participants completed the pre-survey, the counseling student drew the pedigree and provided a risk assessment. After the risk assessment was complete and any questions the participants had were answered, the participants completed the post-survey, which consisted of questions about risk perception, intention to change physical activity habits, and medical research. (See Appendix D). Participants were then given the option to provide written informed consent to enroll in the Minority Research Recruitment Database. At the conclusion of the session, the counseling students asked the participants for permission to contact them again approximately one month later to complete a follow-up survey, which consisted of questions about the participant's experience, changes in family history, information sharing and seeking behaviors, changes in physical activity, and other health-promoting changes. (See Appendix E).

QUESTIONNAIRES

This thesis used data from the questions about demographic information and physical activity habits on the pre-survey, the questions about intention to change physical activity habits and risk perception on the post-survey, and the questions about physical activity habits on the follow-up survey.

Pre-survey-Section 1: General Information

Section 1 of the pre-survey asked participants to provide general demographic information, including age, gender, ethnicity, race, total household income, education level, knowledge on genetics, general health rating, smoking status, weight perception, insurance status, and whether or not individuals had a primary care physician and if they could not see a doctor because of cost.

Pre-survey-Section 2: Physical Activity Habits

Section two of the pre-survey provided participants with a definition of the national recommendation for regular physical activity, which was obtained for the Centers for Disease Control and Prevention (34). Individuals were asked to stage themselves using the transtheoretical model according to their current physical activity habits or their intention to begin. If individuals reported that they were not physically active according to the definition, they were asked whether or not they got any physical activity at all.

Post-survey-Section 1: Physical Activity Habits

Section one of the post-survey asked individuals whether or not they intended to increase their physical activity after the family health history session.

Post-survey-Section 2: Risk Perception

Section two of the post-survey asked individuals to estimate their chances of developing a health condition based on their family history. The health conditions included: breast cancer, ovarian cancer, colon cancer, prostate cancer, cardiovascular disease, lung cancer, diabetes,

Alzheimer's disease, and hypertension. Individuals were asked to rate their risk as Low, Moderate, or High; they also had the option of answering that they did not know or were not sure and that they already had the health condition in question. Similarly, individuals were asked to compare their risk for each health condition to other people. They were given the answer choices: Much lower, Somewhat lower, Same, Somewhat higher, Much higher, Don't know/not sure, and I already have the condition.

Follow-up survey

The questions on this survey were asked by the genetic counseling students over the phone. The genetic counseling students provided participants with the definition of physical activity again and participants responded whether or not they fit the definition. If they answered yes, they were asked if they had been physically active for more or less than six months. If they answered no, they were asked if they intended to become physically active in the next 30 days or six months or if they did not intend to become physically active within the next six months. If the participants responded that they did not meet the definition of physical activity, they were asked if they had increased their physical activity since the family health history session. They were also asked to describe what type of physical activity they performed.

PEDIGREE ANALYSIS

As previously discussed, Scheuner et al. established criteria for assessing the risk for developing many common diseases based on family history (20). (See Figure 2). Each study participant's family history was analyzed to establish high, moderate, or average risk for heart disease,

hypertension, diabetes, breast cancer, ovarian cancer, colon cancer, prostate cancer, and Alzheimer's disease. Scheuner's definition of premature onset was used for coronary artery disease, diabetes, and cancer. The definition of premature Alzheimer's disease was established by the Alzheimer's association to be 65 or younger (35). The definition of premature hypertension was not available, but the genetic counseling students agreed on age 50 or younger to be conservative. Each pedigree was analyzed by two genetic counseling students. Any discrepancies were discussed between the two students and, if not resolved, presented to a third genetic counseling student.

High Risk	Moderate Risk	Average Risk
<ol style="list-style-type: none"> 1. Premature disease in a first degree relative 2. Premature coronary artery disease in a second degree relative 3. Two affected first degree relatives 4. A first degree relative with late/unknown onset of disease and an affected second degree relative from the same lineage with premature disease 5. Two second degree maternal or paternal relatives with at least one having premature disease 6. Three or more maternal or paternal relatives 7. The presence of moderate risk on both sides of the family 	<ol style="list-style-type: none"> 1. A first degree relative with late or unknown onset of disease 2. Two second degree relatives from the same lineage with late or unknown disease onset 	<ol style="list-style-type: none"> 1. No affected relatives 2. One affected second degree relative from one or both sides of the family 3. No known family history 4. Adopted individual with unknown family history
<p>Premature coronary artery disease: 55 or younger in males; 65 or younger in females.</p> <p>Premature stroke, diabetes, colon cancer, and prostate cancer: 50 or younger</p> <p>Premature breast, ovarian, and endometrial cancer: 50 or younger or premenopausal</p>		

Figure 2. Scheuner's Risk Stratification

CONTROLS

A group of individuals in HBFP who had not completed a family health history session were used as controls. These individuals had completed a Health Risk Assessment, a service provided by Highmark that allows individuals to have free health screening. A genetic counseling student reviewed a list of the names of individuals who had completed the Health Risk Assessment and removed any individuals who had completed a family health history session. She then attempted to contact the remaining individuals by phone; after making contact, she obtained verbal consent to ask them some brief questions for a research study looking at the effects of different parts of HBFP. Once consent was given, the counseling student asked the controls questions about their physical activity. (See Appendix F). Their age and gender were obtained from reports generated by Highmark after the Health Risk Assessment.

Health Risk Assessment Survey

The questions on this survey were asked by a genetic counseling student over the phone. The genetic counseling student provided participants with the definition of physical activity and participants responded whether or not they fit the definition. If they answered yes, they were asked if they had been physically active for more or less than six months. If they answered no, they were asked if they intended to become physically active in the next 30 days or six months or if they did not intend to become physically active within the next six months. If the participants responded that they did not meet the definition of physical activity, they were asked if they had

increased their physical activity since the health risk assessment. They were also asked to describe what type of physical activity they performed.

DATA ANALYSIS

Each pre-survey, post-survey, follow-up survey, and health risk assessment survey was entered into online versions of the questionnaires using Perseus SurveySolutions 6[®] and then exported into Excel[®] spreadsheets. Once in the Excel spreadsheet, the data was compared to the participants' responses on their original surveys to verify the accuracy of the data. The family history risk assessments for hypertension, heart disease, and diabetes were added to the survey data. The counts for each analysis were obtained through an Excel pivot table and converted to percentages. The data was then statistically analyzed with χ^2 tests using R[®] statistical package. The data analysis focused on comparing physical activity between cases and controls and looking for any patterns of change in the cases based on different variables, including demographic information and disease risks.

3.0 RESULTS

The results of this thesis focus on the fourth specific aim of the study—assessing whether or not a family health history is effective in encouraging participants to increase their physical activity. This aim was accomplished by comparing study participants to individuals who did not complete a family health history session and by comparing different variables among study participants to identify any differences in physical activity habits. During this study, 124 individuals completed a family health history session with a genetic counseling student; 112 (90.3%) of these individuals agreed to complete the pre- and post-surveys to enroll in the study. When completing the pre-survey, two individuals did not answer the questions about their physical activity habits and were thus excluded from the data analysis. Similarly, 13 of the 112 participants could not be reached for the follow-up survey and are not included in the data analysis. Thus, the data presented in this thesis is from a total of 97 individuals for whom both pre-data and follow-up data could be obtained. These 97 individuals are compared to a total of 91 controls.

DEMOGRAPHICS

Demographic information collected on the study participants included age, gender, race and ethnicity, income, and education level. Information about age, gender, and race was collected for the controls. All individuals were African American and no significant difference between the cases and controls existed for age and gender (See Tables 6-7 in Appendix A).

STAGE OF PHYSICAL ACTIVITY

Cases versus Controls

Individuals who completed a family health history session and agreed to participate in the study were asked about their stage of physical activity both before and after the session. The controls were contacted after their Health Risk Assessment and asked what stage of physical activity they were in and whether or not they had increased their physical activity since their Health Risk Assessment. Stage 1 is maintenance; stage 2 is action; stage 3 is preparation; stage 4 is contemplation; and stage 5 is precontemplation. (See Table 1). Three more individuals reported being physically active after the family health history session than before, whereas 12 fewer individuals reported planning on becoming physically active in the next 30 days. Without the post-data on the 13 individuals who were lost to follow-up, it is difficult to assess the effect of the family history compared to the control group. When these individuals were removed from the analysis, the difference in the numbers of people in maintenance or action improved from the

pre-survey to the follow-up survey. (See Table 9 in Appendix A). Fifty-eight (63.7%) of the controls reported that they had not increased their physical activity since their Health Risk Assessments, whereas 33 (36.3%) individuals reported they had. Of the 41 cases who were not physically active at the time of the follow-up survey, 10 (24.4%) individuals reported that they had not increased their physical activity since the family health history session whereas 31 (75.6%) reported that they had. (See Table 8 in Appendix A).

Table 1. Stage of Physical Activity

Stage	1	2	3	4	5	N/A	Total
Pre-survey	33	22	44	11	0	2	112
Follow-up survey	37	21	32	7	2	13	112
Controls	44	9	28	6	4	0	91

P=0.045

Case Comparison

The remainder of the data analyzed focused on differences within the case population. The 97 individuals who reported a pre-survey stage and a follow-up survey stage were used for this analysis. The difference between their pre-survey stage and follow-up-survey stage is displayed in Table 2. A negative number implies that they improved along the stages; a zero denotes no change; and a positive number indicates a regression along stages. The number indicates the number of stages they moved.

Table 2. Change in Physical Activity Stage from Pre-Survey to Follow-up Survey

Difference	-3	-2	-1	0	1	2	4	Total
	1	11	16	50	12	6	1	97

Twenty-eight (29%) individuals improved after the family health history session, whereas 19 (19%) individuals regressed. (See Table 10 in Appendix A). Although 50 (52%) of these individuals did not change stages, over half (27) of these individuals were already physically active before the family history. (See Table 11 in Appendix A). Of the 21 individuals who remained in stage three, 14 (67%) people increased their physical activity after the family health history session, but not enough to meet the definition of regular physical activity. When the individuals who did change from stage 1 or stage 2 were removed from the analysis, 40% of the remaining individuals improved along the stages. (See Table 12 in Appendix A).

The variables that were measured to detect any differences in the pattern of stage change included demographic information, self-reported health status, weight perception, the intention to change physical activity habits, the value placed on family history and the lack of physical activity as risk factors for disease, and perceived and actual risk for disease. Each of these variables was compared for the 97 individuals for whom pre- and follow-up data was available. In some instances, the individuals who did not change from stage 1 or stage 2 were removed to identify any differences among individuals who had the opportunity to increase their physical activity.

Demographic Comparison

The demographic information for all 97 individuals was compared to detect any differences between people who improved, did not change, and regressed. (See Tables 13-16 in Appendix A). The gender and age group of the individual did not affect changes in physical activity. The differences in education level groups came the closest to approaching significance, but no discernable patterns within the groups are evident. Individuals whose income was less than \$20,000 were somewhat more likely to improve than other individuals.

Health Status and Weight Perception Comparison

Individuals were also compared according to their self-rated health status, but no clear patterns of difference were recognized. (See Table 17 in Appendix A). Similarly, individuals were asked to provide a perception of their weight. Individuals who perceived themselves to be obese were somewhat more likely to increase their physical activity than individuals who perceived themselves to be overweight or a healthy weight. (See Table 18 in Appendix A). Weight perception was also compared to the individuals' stage of exercise before the family health history session to determine if their perceptions were related to their level of physical activity; no discernable pattern was evident. (See Table 19 in Appendix A).

Importance of Family History and Lack of Physical Activity

Participants were asked if they thought a family history of disease never, sometimes, or always contributed to their risk of that disease. Similarly, they were asked if they thought a lack of physical activity never, sometimes, or always increased the risk of disease. The answers of individuals who improved, did not change, and regressed along the stages of change were compared, but no clear pattern emerged. (See Tables 20-21 in Appendix A).

Intention to Change

Immediately after the risk assessment during the family health history session, individuals were asked if they intended to increase their physical activity. The individuals who answered yes to this question were compared to the individuals who answered no to see if there was a difference in the actual stage change. Individuals who intended to increase their physical activity were somewhat more likely to increase their physical activity. (See Table 22 in Appendix A).

Disease Risk

The next step in the data analysis was to compare any differences in physical activity change to individuals' risk for disease. Individuals with a high, moderate, or average risk for different diseases were analyzed. First, the data for cardiovascular disease, hypertension, and diabetes were compared separately. Individuals with a moderate risk for hypertension or diabetes were somewhat more likely to improve than individuals with a high or average risk; the same trend was not seen in cardiovascular disease. (See table 23 in Appendix A). The data for each disease was also combined to create a risk for any disease. With this approach, it became clear that individuals with a moderate risk for any disease were somewhat more likely to increase their physical activity than individuals with a high or average risk. (See Table 24 in Appendix A). When the individuals who did not change from stage 1 or stage 2 were removed from the analysis, the individuals at moderate risk for any disease were particularly likely to improve in comparison with other individuals. (See Table 3).

Table 3. Risk for Any Disease in Individuals Who Were Not Physically Active Before A Family Health History Session

	Improvement	No Change	Regression
Average	3 (30%)	4 (40%)	3 (30%)
Moderate	6 (67%)	3 (33%)	0 (0%)
High	19 (38%)	16 (31%)	16 (31%)

P=0.42

Similarly the data on individuals' risk perception were compared. Again, the data for each disease was first compared separately. (See Table 24 in Appendix A). For each disease, individuals who perceived themselves to be at high risk or who reported already having the disease were slightly more likely to improve along the stages. The data for each disease was again combined to assess the risk perception for any disease. Similarly, individuals who perceived themselves to be at high risk or who reported already having any disease were somewhat more likely to improve along the stages than individuals who perceived themselves to be at moderate or average risk. (See Table 25 in Appendix A). When the individuals who did not change from stage 1 or stage 2 were removed from the analysis, individuals who perceived themselves to be at high risk or who reported already having any disease were again more likely to improve. (See Table 4).

Table 4. Perceived Risk for Any Disease in Individuals Who Were Not Physically Active Before A Family Health History Session

	Improvement	No Change	Regression
Average	0 (0%)	0 (0%)	1 (100%)
Moderate	6 (32%)	9 (47%)	4 (21%)
High/Already Have	22 (44%)	14 (28%)	14 (28%)

P=0.45

To determine how these two analyses corresponded, perceived risk was compared to actual risk. Most individuals perceive themselves to be at high risk or report that they already have a disease regardless of what their risk is based on family history. Specifically, individuals who have a moderate risk for disease are more likely to perceive that they have high risk or to already have a disease. Of individuals who perceive themselves to be at high risk or who report already having a disease, the majority actually do have high risk for disease based on family history. (See Table 5).

Table 5. Perceived Risk versus Actual Risk for Any Disease

	Perceived Risk			
		Average	Moderate	High/Already Have
	Average	0 (0%)	0 (0%)	14 (21%)
	Moderate	0 (0%)	5 (17%)	11 (17%)
	High	2 (100%)	24 (83%)	41 (62%)

P=0.077

4.0 DISCUSSION

As a whole, HBFP and its Family Health History Initiative continue to be a success. Over 2,000 individuals have joined HBFP by attending an orientation session. Individuals who join consistently report sharing information about the project with family members, friends, and co-workers. In the six months of this study, 124 individuals completed a family health history session, indicating a desire to understand the role of family history in risk for disease. Of these 124 individuals, 78 (63%) joined the Minority Research Recruitment Database, indicating a willingness to consider participating in clinical research. All of the participants in this study are African American, providing information on a population completely comprised of minorities, unlike previously published data on the effects of a family health history and the transtheoretical model.

4.1 DEMOGRAPHICS

When comparing age, gender, income, and education level, no significant difference in the likelihood to increase physical activity existed between cases and controls or among cases. When comparing physical activity habits of the cases according to income, it appeared that individuals who earned less than \$20,000 a year were somewhat more likely to improve along

the stages of change than other individuals. This is likely unrelated to the effect of a family health history session, but more an encouraging sign that HBFP is providing a service to individuals who could not previously afford access to quality physical activity opportunities.

Although no significant difference in physical activity increase existed between gender, men are still vastly underrepresented in the data analysis, as reported in previous thesis studies on this project. In both cases and controls, women comprise almost 90% of the study population. Attempts to recruit men at community events targeted for them have been largely unsuccessful, primarily because of a lack of success in making inroads with these community leaders and organizers. Men rarely attend family health history sessions alone; the highest success with recruiting men is to have them attend a session with their wives. This finding is consistent with research that indicates that women are responsible for health-care seeking behavior for both themselves and their family members (36, 37).

4.2 STAGE OF PHYSICAL ACTIVITY

Cases versus Controls

Broadly, it seems that individuals who completed a family health history session were more likely to increase their physical activity than individuals who completed a health risk assessment. Approximately 36% of individuals who completed a health risk assessment reported increasing their physical activity afterwards. Although not all individuals who completed a family health history session were asked if they increased their physical activity after meeting with a genetic counseling student, the majority of those that were reported an increase. Approximately 76% of

individuals who were not in maintenance or action at the time of the follow-up survey stated that they had increased their physical activity since the time of the family health history session.

One interesting finding in the case-control comparison is that a large number of controls reported being in the maintenance stage. No obvious explanation for this result exists. The controls were randomly called from a list of individuals who had completed their health risk assessments and no information was known about them. It is possible that the group of individuals who could be reached and who agreed to answer the questions happened to be more physically active than the general population and the cases by chance. The controls could, however, be misreporting their amount of physical activity; the genetic counseling student never saw these individuals and could not make an assessment of their level of physical activity based on their appearance. Alternatively, an age could not be obtained for 15% of the controls; it is possible that these individuals fall into the younger age categories, which may make them somewhat more likely to be physically active. If this is the case, then the ages of the cases and controls would not be as similar and that could explain the discrepancy in the numbers of individuals reporting being in the maintenance stage.

Change in Physical Activity After a Family Health History Session

The majority (52%) of individuals did not move along the stages of change after a family health history session. Twenty seven of the 50 individuals who did not change in stage were already physically active, being in the action or maintenance stages and they would not be expected to move. Once these 27 individuals were removed from the analysis, more individuals improved along the stages than either did not change or regressed. Forty percent of the remaining 70 individuals improved along the stages, whereas 33% did not change and 27% regressed. Of the

23 remaining individuals who did not change stages, 15 (65%) reported an increase in physical activity after the family health history session although they still did not meet the definition of physical activity.

Most individuals (57%) who improved along the stages improved one stage. Thirty –nine percent of individuals who improved moved up two stages and 4% of individuals moved up three stages. For the time between the family health history session and the follow-up phone call, this seems like a reasonable improvement. Similarly, most individuals (63%) who regressed in stage only moved down one stage. Twenty one percent of individuals who regressed moved down from maintenance to action. Most individuals completed a family health history session before the holiday season and their follow-up was completed after the holidays; it is possible that these individuals stopped their regular physical activity routines for the holidays and then resumed them.

Intention to Change

Immediately after the risk assessment during the family health history assessment, individuals were asked whether or not they intended to increase their physical activity; 89% of individuals responded that they thought they would increase their physical activity. Only 29% of those individuals actually improved along the stages of change. In comparison, 20% of individuals who did not intend to increase their physical activity improved along the stages of change. Although individuals who did intend to change were slightly more likely to improve than individuals who did not intend to change, the difference is not striking. One mediating factor is the small number of people who did not intend to increase their physical activity; only 10 individuals responded no to this question; it is therefore possible that the percentage of

individuals who did improve was similar to those who answered yes just by chance. The fact that a significant difference does not exist between these two groups is not surprising because the intention to change does not consistently correspond to an actual change.

Weight Perception

Individuals were asked to provide a perception of their weight; the choices included: underweight, healthy weight, overweight, and obese. No one perceived themselves to be underweight. The majority of individuals (59%) perceived themselves to be overweight. A correlation between weight perception and pre-survey physical activity stage might be expected, with individuals perceiving themselves to be a healthy weight being more likely to be in action or maintenance individuals who perceive themselves to be overweight or obese. This correlation was not observed, indicating that individuals may not be answering the question about their physical activity accurately.

Similarly, individuals who perceive themselves to be overweight or obese would be expected to be more likely to increase their physical activity than individuals who perceive themselves to be a healthy weight. Encouragingly, 53% of individuals who perceived themselves to be obese improved along the stage of change, whereas less than 30% of individuals who perceived themselves to be overweight or a healthy weight increased. The number of individuals who perceived themselves to be obese was fairly small (only 15 individuals), and this trend may have occurred by chance.

Disease Risk

When comparing individuals' likelihood to improve along the stages of change according to their actual disease risk, it seemed that those at moderate risk for any disease were more likely to improve along the stages than individuals at high or average risk. Only 16% of individuals were at moderate risk for any disease, so this trend could have appeared by chance due to the small sample size. In fact, most individuals (69%) have a high risk for hypertension, diabetes, or heart disease. The likelihood that a change in physical activity truly corresponds with risk for disease would only be expected if participants have accurate risk perceptions. The actual risk of participants did not, however, consistently correspond to their perceived risk. Most individuals (68%), regardless of their actual risk, either already had one of the conditions (hypertension, diabetes, or heart disease) or perceived themselves to be at high risk. These individuals were more likely to improve along the stages than individuals who perceived themselves to be at average or moderate risk.

This finding is consistent with some other studies that have reported an increase in health protective behaviors in individuals who perceive themselves to have an increased risk for disease. As mentioned above, Hunt et al. reported that individuals with a family history of heart disease who perceive themselves to be at increased risk for developing heart disease are less likely to smoke than other individuals (23). Similarly, Forsyth et al. reported that individuals with a parental history of diabetes perceive themselves to be at higher risk for diabetes and that they report more frequent protective behaviors, including weight reduction, diet, exercise, and regular visits to their doctors (16). Lerman et al. reported that women who had a higher perceived vulnerability to breast cancer were more likely to engage in repeated mammography (38). Likewise, Bowen et al. found that women who had higher perceived risks for breast cancer

were more likely to enroll in a breast cancer risk counseling session (39). Higher perceived risk, then, may be an incentive to engage in health protective behaviors such as increased screening, improved diet, smoking cessation, and physical activity.

Other Variables

Most of the variables analyzed did not reveal any differences in patterns of change. For some of these analyses, the lack of significance was not surprising. For instance, a difference among individuals in different demographic groups would not be expected. For other analyses, a difference among individuals might be expected. For instance, one might expect that individuals who report being in fair or poor health would be more likely to increase their physical activity to improve their health. Conversely, these individuals may be less likely to increase their activity level because they are not physically able to. Neither of these patterns was observed. Additionally, individuals who believe that family health history and a lack of physical activity always contribute to disease risk would also be expected to increase their physical activity more than other individuals, but no such findings emerged from the study.

4.3 LIMITATIONS OF THIS STUDY

This study had several limitations. The primary concern was the lack of sufficient numbers of participants to discern any significant differences between groups of people. Although the total number of participants (n=112) was seemingly large enough to allow for determination of

whether or not a family health history session is effective in encouraging increased physical activity, the nature of the project required a larger sample. Because this analysis required participants to be contacted by phone after the initial meeting, loss to follow-up became an issue. Thirteen percent of the study population could not be reached for follow-up, either because of a disconnected phone or because of lack of availability. With complete data available on only 97 individuals, it became difficult to discern if any significant patterns were present. All of the data analyses required dividing the total sample into smaller groups, some of which consisted of only 1 or 2 members. Because of such small sample sizes, the data analysis did not have the power to detect whether or not any trends that were observed were significant or arbitrary.

This study relied on self-report that could not be verified. A larger-than-expected number of individuals (49%) reported already being physically active before the family health history session. National data on physical activity reports that only 25% of African Americans meet the recommendations for physical activity (3,4). Either this study is recruiting individuals who are better able to meet the national requirements or the participants are misinterpreting the definition of physical activity or misreporting their amount of physical activity. The latter scenario is the more likely case. Seventy-four percent of the study population perceive themselves to be overweight or obese, which is consistent with national statistics that estimate 77% of African American women are overweight (2). Anecdotal observation from the genetic counseling students also supports the theory that participants are not accurately reporting their level of physical activity; most of the participants are women who appear to be overweight or obese and do not likely get the amount of physical activity they report. Some of this error is probably inevitable in that participants will answer the questions about physical activity the way they think they should answer it.

The method of data collection also had limitations. On the pre-survey, the definition of physical activity is fairly long; this type of definition was chosen because Richards Reed et al. suggested it allowed for the most accurate responses (31), but it seemed that in an effort to complete the survey quickly, some participants did not read the entire definition closely. As a result, the possibility exists that individuals who did not meet the definition of physical activity but who got some physical activity answered yes, putting themselves in stage 1 or stage 2. A shorter definition simply asking: “Do you get 30 minutes of physical activity a day for 5 or more days a week?” may be more appropriate.

Additionally, there was a discrepancy in how the staging question was presented between the pre-survey and the follow-up survey. Individuals read the question and circled the appropriate response themselves on the pre-survey, but they were read the question over the phone by a genetic counseling student who then circled their response on the follow-up survey. If the participants did not interpret the question correctly when they answered it on the pre-survey, the possibility of a discrepancy in their responses exists. Although meeting with participants a second time to have them fill out a follow-up survey is not feasible, it may be possible to have a genetic counseling student orally ask the participants about their physical activity habits before the family health history session for consistency in the questioning method. Another aspect that should be added to the pre-survey questions about physical activity is to assess what type of physical activity the participants engage in. They are asked this question on the follow-up survey, but, at present, no pre-survey data exists to compare the answers with to detect any changes.

Although having information about other individuals in HBFP is useful, the data collected on the controls was difficult to compare to the data on the individuals who completed a

family health history. Because no pre-health risk assessment data was available for the controls, their post-assessment stage of physical activity data was not useful. Instead, it was only practical to use the data on whether or not they increased their physical activity and compare it to the data on individuals who completed a family health history. Individuals who reported being physically active on the follow-up survey, however, were not asked if they had increased their physical activity; only individuals who were in the preparation, contemplation, or pre-contemplation stages were asked whether or not they increased their physical activity after the family health history session. Collecting follow-up information about increase in physical activity for all individuals completing a family health history session, then, would be helpful both in comparing them to controls and in assessing the effect of a family health history session if the stages of change data is not telling. Finding a way to collect pre-assessment data on the controls would also be useful, although it may not be feasible.

Lastly, it is difficult to discern whether or not any improvements made in physical activity are due solely to the family health history session or are instead due to the HBFP as a whole. The control arm of this study was intended to assess any differences in the various parts of the project, but this part of the study had limitations as discussed above. Further, individuals who completed a family health history session are more likely to have attended an orientation session than individuals who completed a health risk assessment because almost all of the recruitment for family health history sessions occurs at orientation sessions. Individuals who have attended orientation sessions have the information about how to gain access to the physical activity opportunities in the project and can participate in them whether or not they complete a family health history session. Thus, any difference in physical activity increase between cases

and controls may simply due to increased participation in all aspects of HBFP rather than to an effect of a family health history session.

4.4 INDICATIONS FOR FUTURE STUDIES

This data analysis would benefit from a larger study number and from the changes in the data collection methods as mentioned above. Thus, repeating this study at a later time would be beneficial. An additional option for strengthening the analysis would be to verify participants' type and frequency of physical activity. Records on HBFP class attendance are kept and could be cross-referenced with self-report by study participants. This method of verification would not capture information about any physical activity done outside of HBFP, but it would provide some tangible support for self-reported actions. Verification of other data, including BMI and quantitative biochemical measurements like blood pressure, cholesterol, and blood sugar levels, would also be useful to track any benefits of physical activity; this data could be obtained by merging different databases from the Family Health History Initiative and the Highmark Health Risk Assessments.

Although this study focused on the effects of a family health history session on physical activity behavior, the goals of this initiative extend beyond physical activity. The Center for Minority Health hopes that increasing knowledge about the importance of family history as a risk factor for disease will encourage individuals to make a variety of positive lifestyle changes. At present, qualitative data on changes such as improved diet, increased screening, and smoking

cessation are being collected with the follow-up survey. Future studies could design a way to analyze this data or could create new quantitative ways to measure other behavior changes.

The Center for Minority Health is also interested in collecting information about what individuals do with the information they receive during a family health history session. The hope is that a family health history session encourages both information-sharing and information-seeking behaviors. Currently, participants are asked if they shared or intend to share the information about their family health history with other family members and with their doctors during the follow-up survey phone call. The data collected from these questions could be analyzed qualitatively or a new method of data collection could be utilized to garner quantitative results about information-sharing behavior. At present, no consistent way to gather information about information-seeking behavior has been established. Future studies could investigate an academically sound way to gather this information.

Lastly, although a previous thesis project characterized the differences between individuals who enrolled in the Minority Research Recruitment Database and those who declined enrollment, little other work on the database has been performed. To date, only 29 of the 253 individuals who are in the database have received information about a clinical research study for which they may be eligible. A more proactive approach to searching for clinical trials for which our database participants are eligible may be warranted to increase the number of individuals who receive information about clinical trials. Once the number of individuals who have been sent information about clinical research is larger, a study investigating what they do with the information will be useful.

4.5 CONCLUSIONS

Despite the limitations of this study and the lack of significant findings in the data, I still consider this project a success. We have continued to enroll a large number of African Americans in our research study by creating trusting relationships in the communities in which we work. I have learned a great deal about how to create trust as a health care professional from my mentors at CMH and from my own experiences in Pittsburgh's African American community. By creating this trust, I have been able to affect the lives of many individuals. I know that my work has made a difference in the community because the members of this community have repeatedly told me just that. They value the work we are doing and I will take those memories with me when I leave. Although this project has flaws, it has been an invaluable experience for me and it has provided the study with a solid foundation and has illuminated what kinds of changes we can make to improve our data collection and make the study stronger

APPENDIX A

TABLES OF RESULTS

Table 6. Gender Distribution

	Cases	Controls
Gender		
Female	97 (87%)	80 (88%)
Male	15 (13%)	11 (12%)
Total	112	91

Table 7. Age Distribution

	Cases	Controls
Age Group		
18-35	10 (9%)	9 (10%)
36-50	28 (25%)	25 (28%)
51-65	51 (45%)	22 (24%)
Over 65	23 (21%)	21 (23%)
Unknown	0 (0%)	14 (15%)
Total	112	91

Table 8. Increase in Physical Activity

	Cases	Controls
Increase	31 (76%)	33 (36%)
No increase	10 (24%)	58 (64%)
Total	41	91

Table 9. Stage of Physical Activity for Individuals Not Lost to Follow-up

Stage	1	2	3	4	5	Total
Pre-Survey	30	19	40	8	0	97
Follow-up Survey	37	21	32	7	2	97
Controls	44	9	28	6	4	91

Table 10. Direction of Stage Change for Cases

Change	Improvement	No Change	Regression
	28 (29%)	50 (52%)	19 (19%)

p<0.0001

Table 11. Pre- and Follow-up Stage of Individuals Who Did Not Change

Stage	1	2	3	4	5
	21	6	21	2	0

Table 12. Change in Stage for Individuals Who Were Not Physically Active Before the Family Health History Session

Stage Change	Improvement	No Change	Regression
	28 (40%)	23 (33%)	19 (27%)

p=0.18

Table 13. Gender Comparison in Cases

	Improvement	No Change	Regression
Female	25 (29%)	44 (52%)	16 (19%)
Male	3 (25%)	6 (50%)	3 (25%)

p=0.87

Table 14. Age Group Comparison in Cases

	Improvement	No Change	Regression
18-35	2 (29%)	3 (43%)	2 (29%)
36-50	8 (34%)	11 (46%)	5 (21%)
51-65	13 (31%)	24 (56%)	6 (14%)
Over 65	5 (22%)	12 (52%)	6 (26%)

p=0.87

Table 15. Education Level Comparison in Cases

	Improvement	No Change	Regression
Grade 9-11	1 (25%)	1 (25%)	2 (50%)
Grade 12 or GED	10 (45%)	7 (32%)	5 (23%)
College 1-3 years	8 (18%)	30 (68%)	6 (14%)
College 4 or more years	6 (40%)	5 (33%)	4 (27%)
Graduate degree	3 (25%)	7 (58%)	2 (17%)

p=0.098

Table 16. Income Comparison in Cases

	Improvement	No Change	Regression
Less than \$20,000	15 (37%)	20 (49%)	6 (14%)
\$20,001-\$35,000	6 (23%)	12 (46%)	8 (31%)
\$35,001-\$50,000	2 (17%)	9 (75%)	1 (8%)
Greater than \$50,000	3 (25%)	7 (58%)	2 (17%)

p=0.37

Table 17. Self-Reported Health Comparison in Cases

	Improvement	No Change	Regression
Excellent	1 (100%)	0 (0%)	0 (0%)
Very Good	0 (0%)	10 (77%)	3 (23%)
Good	10 (17%)	30 (50%)	20 (33%)
Fair	15 (56%)	9 (33%)	3 (11%)
Poor	2 (67%)	1 (33%)	0 (0%)

Table 18. Weight Perception Comparison in Cases

	Improvement	No Change	Regression
Healthy Weight	7 (29%)	16 (67%)	2 (8%)
Overweight	13 (23%)	31 (54%)	13 (23%)
Obese	8 (53%)	3 (20%)	4 (27%)

p=0.04

Table 19. Weight Perception According to Pre-Survey Physical Activity Stage

Pre-Survey Stage	1	2	3	4
Healthy Weight	10 (30%)	4 (18%)	10 (23%)	4 (36%)
Overweight	22 (67%)	14 (64%)	22 (50%)	7 (64%)
Obese	1 (3%)	4 (18%)	12 (27%)	0 (0%)
Total	33	22	44	11

Table 20. The Contribution of Family History to Disease Risk

	Improvement	No Change	Regression
Never	0 (0%)	2 (100%)	0 (0%)
Sometimes	17 (39%)	20 (45%)	7 (16%)
Always	8 (18%)	24 (55%)	12 (27%)
Don't Know	2 (33%)	4 (67%)	0 (0%)

Table 21. The Contribution of Lack of Physical Activity to Disease Risk

	Improvement	No Change	Regression
Never	0 (0%)	1 (100%)	0 (0%)
Sometimes	8 (31%)	15 (58%)	3 (12%)
Always	19 (28%)	33 (49%)	16 (24%)
Don't Know	0 (0%)	1 (100%)	0 (0%)

Table 22. Intention to Increase Physical Activity

	Improvement	No Change	Regression
Yes	25 (29%)	43 (51%)	17 (20%)
No	2 (20%)	6 (60%)	2 (20%)

Table 23. Specific Disease Risk

	Improvement	No Change	Regression
Heart Disease			
Average	9 (28%)	15 (47%)	8 (25%)
Moderate	7 (28%)	16 (64%)	2 (8%)
High	12 (30%)	19 (48%)	9 (23%)
Hypertension			
Average	3 (15%)	13 (65%)	4 (20%)
Moderate	10 (37%)	16 (59%)	1 (4%)
High	15 (30%)	21 (42%)	14 (28%)
Diabetes			
Average	10 (28%)	16 (44%)	10 (28%)
Moderate	9 (45%)	10 (50%)	1 (5%)
High	9 (22%)	24 (58%)	8 (20%)

Table 24. Risk for Any Disease

	Improvement	No Change	Regression
Average	3 (21%)	8 (57%)	3 (21%)
Moderate	6 (37%)	10 (63%)	0 (0%)
High	19 (27%)	32 (48%)	16 (23%)

p=0.28

Table 25. Specific Disease Risk Perception

	Improvement	No Change	Regression
Heart Disease			
Average	7 (29%)	13 (54%)	4 (17%)
Moderate	8 (22%)	23 (64%)	5 (14%)
High	9 (38%)	10 (42%)	5 (21%)
Already have	3 (38%)	4 (50%)	1 (13%)
Hypertension			
Average	1 (11%)	6 (67%)	2 (22%)
Moderate	7 (25%)	17 (61%)	4 (14%)
High	8 (28%)	14 (48%)	7 (24%)
Already Have	12 (40%)	13 (43%)	5 (17%)
Diabetes			
Average	7 (26%)	14 (52%)	6 (22%)
Moderate	7 (24%)	19 (66%)	3 (10%)
High	8 (36%)	8 (36%)	6 (27%)
Already Have	6 (35%)	7 (41%)	4 (24%)

Table 26. Perceived Risk of Any Disease

	Improvement	No Change	Regression
Average	0 (0%)	1 (50%)	1 (50%)
Moderate	6 (21%)	19 (65%)	4 (14%)
High/Already Have	22 (33%)	30 (46%)	14 (21%)

p=0.31

APPENDIX B

UNIVERSITY OF PITTSBURGH IRB APPROVAL

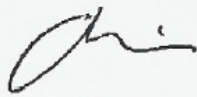


University of Pittsburgh

Institutional Review Board

3500 Fifth Avenue
Ground Level
Pittsburgh, PA 15213
(412) 383-1480
(412) 383-1146 (fax)

MEMORANDUM:

TO: Stephen B. Thomas, Ph.D.
FROM: Christopher Ryan, Ph.D., Vice Chair 
DATE: May 4, 2004
SUBJECT: IRB#: 0403125 HEALTHY BLACK FAMILY PROJECT: Assessing African Americans' Response to Family Health Histories

The above-referenced proposal has received expedited review and approval from the Institutional Review Board under 45 CFR 46.110 (7).

Please note that the advertisement that was submitted for review has been approved as written.

If applicable, please include the following information in the upper right-hand corner of all pages of the consent form:

Approval Date: 05/03/2004
Renewal Date: 05/02/2005
University of Pittsburgh
Institutional Review Board
IRB# 0403125

Adverse events which occur during the course of the research study must be reported to the IRB Office. Please call the IRB Adverse Event Coordinator at 412-383-1145 for the current policy and forms.

The protocol and consent forms, along with a brief progress report must be resubmitted at least one month prior to the expiration date noted above for annual renewal as required by FWA00006790 (University of Pittsburgh), FWA00006735 (University of Pittsburgh Medical Center) and FWA00006600 (Children's Hospital of Pittsburgh).

Please be advised that your research study may be audited periodically by the University of Pittsburgh Research Conduct and Compliance Office.

CR:ky

APPENDIX C

PRE-SESSION SURVEY

An important aim of genetic counseling is to provide risk information so that individuals and families can make better informed decisions about their health and that of their families. The purpose of this survey is to explore your perceptions of risk for developing certain health conditions. We want to understand whether family health histories (i.e., sharing information about diseases in your family) can help provide you with a more accurate assessment of your risk for developing particular health conditions.

If there is a question that you do not feel comfortable answering, you can skip it and continue on. Please answer the following questions to the best of your ability. **DO NOT PROVIDE ANY NAMES OF FAMILY MEMBERS.** The survey should take approximately 10 minutes. Thank you for your time.

Section 1: General Information

1) What is your age?

— — age in years

2) What is your gender?

1 Male

2 Female

3) Are you Hispanic or Latino?

1 Yes

2 No

3 Don't know

3a) Which one or more of the following would you say is your race? **(Check all that apply)**

1 White

2 Black or African American

3 Asian

4 Native Hawaiian or Other Pacific Islander

5 American Indian, Alaska Native

6 Other [specify] _____

4) What was the total household income from all sources last year?

- 1 Less than \$10,000
- 2 Between \$10,000 and \$20,000
- 3 Between \$20,001 and \$35,000
- 4 Between \$35,001 and \$50,000
- 5 Between \$50,001 and \$75,000
- 6 Greater than \$75,000

5) What is the highest grade or year of school you completed?

- 1 Grades 8 or less (Elementary)
- 2 Grades 9 through 11 (Some high school)
- 3 Grade 12 or GED (High school graduate)
- 4 College 1 year to 3 years (Some college or technical school)
- 5 College 4 years or more (College graduate or post-graduate)
- 6 Graduate level (Masters or PhD)

6) How would you rate your knowledge on genetics?

- 1 Excellent
- 2 Very good
- 3 Good
- 4 Fair
- 5 Poor

7) How would you describe your general health?

- 1 Excellent
- 2 Very good
- 3 Good
- 4 Fair
- 5 Poor

8) Do you smoke?

1 Yes

2 No

9) How would you describe your weight?

1 Underweight

2 Healthy weight

3 Overweight

4 Obese

10) Do you have one person you think of as your personal doctor or health care provider?

1 Yes, only one

2 More than one

3 No

4 Don't know / Not sure

11) Was there a time in the past 12 months when you needed to see a doctor but could not because of the cost?

1 Yes

2 No

3 Don't know / Not sure

12) Do you have any kind of health care coverage, including health insurance, prepaid plans such as HMOs, or government plans such as Medicare?

1 Yes

2 No

3 Don't know / Not sure

Section 2: Physical Activity Habits

Definition of Physical Activity: The national recommendation for physical activity is engaging in moderate physical activity (walking briskly, mowing the lawn, dancing, bicycling) for 30 minutes a day 5 or more days a week OR engaging in vigorous physical activity (jogging, high-impact aerobics, swimming) for 20-30 minutes a day 3 or more days a week.

11) Based on this definition, are you physically active?

- 1 Yes, I have been for more than 6 months
- 2 Yes, I have been for less than 6 months
- 3 No, but I am planning on starting in the next 30 days
- 4 No, but I am thinking about starting in the next 6 months
- 5 No, and I don't plan to start in the next 6 months

12) If you answered NO to question 11, do you get some physical activity but not enough to fit the definition?

- 1 Yes
- 2 No

Section 3: Risk Perception

13) In your opinion, how often do you believe each of the following factors increases (or contributes to) an individual's chance or risk for developing a disease? **(Please respond for each item listed)**

1=Never 2= Sometimes 3=Always 4=Don't know / Not sure

Smoking	_____
Having a poor diet	_____
Lack of exercise	_____
Family history (other family members with a disease)	_____

14) What do you think the chances are of a healthy woman the same age as you to develop the following health conditions sometime in her life? **(Please respond for each condition listed)**

1=Low (<10%) 2=Moderate (10-50%) 3=High (>50%) 4=Don't know /

Not sure

Breast cancer	_____
Ovarian cancer	_____
Colon cancer	_____
Cardiovascular disease	_____
Lung cancer	_____
Diabetes	_____
Alzheimer's disease	_____
Hypertension	_____

15) What do you think the chances are of a healthy man the same age as you to develop the following health conditions sometime in his life? **(Please respond for each condition listed)**

1=Low (<10%) 2=Moderate (10-50%) 3=High (>50%) 4=Don't know /

Not sure

Breast cancer	_____
Colon cancer	_____
Prostate cancer	_____
Cardiovascular disease	_____
Lung cancer	_____
Diabetes	_____
Alzheimer's disease	_____
Hypertension	_____

16) Have you ever been concerned about your chances for developing any of these health conditions?

1 Yes

2 No

16a) If yes, which one(s)? _____

17) On a scale from 1 (not concerned) – 5 (extremely concerned), how would you rate your concern about developing any of the above health condition(s)? _____

18) Do you have a blood relative (mother, father, sister, brother, uncle, aunt, grandmother, grandfather) who had or has a health condition that you are concerned about developing sometime in your life?

1 Yes

2 No

3 Don't know / Not sure

18a) If yes, who and what was the health condition? ***DO NOT INCLUDE NAMES OF FAMILY MEMBERS, ONLY THE RELATIONSHIP TO YOU**

19) Have you ever talked to a health provider about your concern for developing that particular health condition?

1 Yes

2 No

3 Don't know / Not sure

19a) If yes, which one(s)? _____

20) At this time, what do you think your chances are of developing any of the following health conditions sometime in your life? **(Please respond for each condition listed)**

1=Low (<10%)

2=Moderate (10-50%)

3=High (>50%)

4=Don't know / Not sure

5=I already have the condition

Breast cancer _____

Ovarian cancer (Females Only) _____

Colon cancer _____

Prostate cancer (Males Only) _____

Cardiovascular disease _____

Lung cancer _____

Diabetes _____

Alzheimer's disease _____

Hypertension _____

21) At this time, what do you think your chances are of developing any of the following health conditions someday, compared with most individuals your age? **(Please respond for each condition listed)**

ML=Much lower

SL=Somewhat lower

S=Same

SH=Somewhat higher

MH=Much higher

DK=Don't know / Not sure

AH=I already have the condition

Breast cancer _____

Ovarian cancer (Females Only) _____

Colon cancer _____

Prostate cancer (Males Only) _____

Cardiovascular disease _____

Lung cancer _____

Diabetes _____

Alzheimer's disease _____

Hypertension _____

APPENDIX D

POST-SESSION SURVEY

We hope that you enjoyed having your family health history done. We would like to ask you a few more questions about risk to see if the family health history session changed your ideas about what conditions you might be at risk for. In addition, this post-session survey is looking at your opinions regarding participating in research.

If there is a question that you do not feel comfortable answering, you can skip it and continue on. Please answer the following questions to the best of your ability. **DO NOT PROVIDE ANY NAMES OF FAMILY MEMBERS.** The survey should take approximately 10 minutes. We would like to thank you in advance for your willingness to participate in this study.

Section 1: Physical Activity Habits

1) Based on our discussion, do you think that you will increase your physical activity?

1 Yes

2 No

Section 2: Risk Perception

2) In your opinion, how often do you believe each of the following factors increases (or contributes to) an individual's chance or risk for developing a disease? **(Please respond for each item listed)**

1=Never

2= Sometimes

3=Always

4=Don't know / Not sure

Smoking

Having a poor diet

Lack of exercise

Family history (other family members with a disease)

3) Based on your family health history, what do you think your chances are of developing any of the following health conditions sometime in your life? **(Please respond for each condition listed)**

1=Low (<10%)

2=Moderate (10-50%)

3=High (>50%)

4=Don't know / Not sure

5=I already have the condition

Breast cancer _____

Ovarian cancer (Females Only) _____

Colon cancer _____

Prostate cancer (Males Only) _____

Cardiovascular disease _____

Lung cancer _____

Diabetes _____

Alzheimer's disease _____

Hypertension _____

4) Based on your family health history, what do you think your chances are of developing any of the following health conditions someday, compared with most individuals your age? **(Please respond for each condition listed)**

ML=Much lower

SL=Somewhat lower

S=Same

SH=Somewhat higher

MH=Much higher

DK=Don't know / Not sure

AH=I already have the condition

Breast cancer _____

Ovarian cancer (Females Only) _____

Colon cancer _____

Prostate cancer (Males Only) _____

Cardiovascular disease _____

Lung cancer _____

Diabetes _____

Alzheimer's disease _____

Hypertension _____

Section 2: Opinions on Research

5) How important do you feel that medical research is?

- 1 Very important
- 2 Somewhat important
- 3 Not very important
- 4 Not important at all
- 5 Don't know

6) Have you ever participated as a subject in any medical research studies?

- 1 Yes
- 2 No
- 3 Don't know

7) Have you ever been offered the chance to participate in a medical research study and decided not to participate?

- 1 Yes
- 2 No
- 3 Don't know

8) If you were to describe your general attitude towards medical research involving people, would you say that you feel?

- 1 Very favorable
- 2 Somewhat favorable
- 3 Somewhat unfavorable
- 4 Very unfavorable
- 5 Neither favorable nor unfavorable
- 6 Don't know

9) Would the offer of free medical care make you more likely or less likely to agree to participate in research?

- 1 More likely
- 2 Less likely
- 3 No effect
- 4 Don't know

10) Would the offer of \$500 make you more likely or less likely to agree to participate in research?

- 1 More likely
- 2 Less likely
- 3 Have no effect
- 4 Don't know

11) Would the offer of free medicine make you more likely or less likely to agree to participate in research?

- 1 More likely
- 2 Less likely
- 3 Have no effect
- 4 Don't know

12) How much do you think scientists benefit from medical research?

- 1 A great deal
- 2 A moderate amount
- 3 Only a little
- 4 Not at all
- 5 Depends

13) How much do you think your community benefits from medical research?

- 1 A great deal
- 2 A moderate amount
- 3 Only a little
- 4 Not at all
- 5 Depends

14) How much do you think your family and friends benefit from medical research?

- 1 A great deal
- 2 A moderate amount
- 3 Only a little
- 4 Not at all
- 5 Depends

15) How much do you think you benefit from medical research?

- 1 A great deal
- 2 A moderate amount
- 3 Only a little
- 4 Not at all
- 5 Depends

16) Do you have an interest in having your name in a database that would allow you to receive information about clinical research studies related to your family health history?

NOTE: Answering YES to this question DOES NOT enter you into any database nor does it sign you up to receive any information.

- 1 Yes
- 2 No

16a) If you answered yes, what are your expectations? **(Please circle all that apply)**

- 1 I expect to receive information about *all* of the latest research studies.
- 2 I expect to receive information about studies that I am eligible for.
- 3 I expect to be rewarded for participating in research (paid, free health care, etc.)
- 4 I expect to get the best health care available.
- 5 Other: _____

16b) If you answered no, what are your primary reasons? **(Please circle all that apply)**

- 1 I am not interested in participating in research.
- 2 I am not interested in anything tied to my family/my genetics.
- 3 I do not want to be part of a database.
- 4 I do not want to disclose my contact information.
- 5 Other: _____

17) How would you describe your experience with having your family health history taken?

(Please circle all that apply)

- 1 Enjoyable
- 2 Informative
- 3 Uncomfortable/Unpleasant
- 4 Neutral/No opinion

APPENDIX E

FOLLOW-UP SURVEY

Date: _____

Person Making Phone Call: _____

INTERVIEWER: ASK TO SPEAK WITH THE INDIVIDUAL WHO GAVE US HIS OR HER NAME AND TELEPHONE NUMBER. IF YOU ARE TOLD THAT THE PERSON IS NOT HOME, SCHEDULE A CALL-BACK. WHEN YOU ARE SPEAKING WITH THE INDIVIDUAL, READ...

Hi, my name is _____ and I am a genetic counseling student from The University of Pittsburgh with the Center for Minority Health. About a month ago, you completed a survey and had your family health history completed at _____. As you may recall, you agreed to let us contact you for a follow-up questionnaire. I just have a couple of brief questions to ask you. It should take about five minutes. Is it okay to proceed with the questions?

1) After having your family health history done, how did it make you feel?

2) Did you tell any one about having your family health history drawn out?

1 Yes

2 No

3) **(IF THE PERSON SAYS YES TO #2)** Who did you tell and what did you tell them?

4) Has anything about your family health history changed since we met?

1 Yes

2 No

5) Did you add (that or) anything else you may have remembered to your family health history?

1 Yes

2 No

6) Did you look over the materials/information we sent you with your family health history?

1 Yes

2 No

7) **(IF THE PERSON SAYS YES TO #6)** Did you find them helpful?

1 Yes

2 No

8) Would you like any additional information?

1 Yes

2 No

9) Have you seen a health care professional since you had your family health history done?

1 Yes

2 No

10) (**IF THE PERSON SAYS YES TO #9**) Did you share your family health history with the health care professional?

1 Yes

2 No

11) (**IF THE PERSON SAYS YES TO #10**) What did he or she say about it?

12) Do you have any plans to share your family health history with your family in the next six months?

1 Yes

2 No

13) Do you plan to share your family health history with a health care professional (i.e., doctor, nurse, pharmacist, physician assistant, or genetic counselor) in the next six months

1 Yes

2 No

14) During our meeting, you answered a question about your physical activity; I am going to read that question to you again to see if your answer has changed.

Definition of Physical Activity: The national recommendation for physical activity is engaging in moderate physical activity (walking briskly, mowing the lawn, dancing, bicycling) for 30 minutes a day 5 or more days a week OR engaging in vigorous physical activity (jogging, high-impact aerobics, swimming) for 20-30 minutes a day 3 or more days a week.

Based on this definition, are you physically active?

- 1 Yes, I have been for more than 6 months
- 2 Yes, I have been for less than 6 months
- 3 No, but I am planning on starting in the next 30 days
- 4 No, but I am thinking about starting in the next 6 months
- 5 No, and I don't plan to start in the next 6 months

15) **(IF THE PERSON SAYS NO TO #14)** Have you increased your physical activity, but not enough to fit the definition?

- 1 Yes
- 2 No

16) What kind of physical activity do you engage in?

- 1 Walking
- 2 Jogging
- 3 Aerobics
- 4 Bicycling
- 5 Housework/yardwork
- 6 Swimming
- 7 Other _____
- 8 None

17) Have you made any other lifestyle changes (diet/smoking/increased screening) since we did your family health history?

1 Yes

2 No

18) **(IF THE PERSON SAYS NO TO #17)** Do you want to or are you planning on making any changes?

1 Yes

2 No

19) **(IF THE PERSON SAYS YES TO #17)** What do you find to be the barriers for you to making changes?

20) **(IF THE PERSON SAYS YES TO #17)** What do you think would help you make the changes you want to? (ie: classes, support groups)

APPENDIX F

HEALTH RISK ASSESSMENT SURVEY

Date: _____

Person Making Phone Call: _____

INTERVIEWER: ASK TO SPEAK WITH THE INDIVIDUAL WHO IS IN OUR DATABASE.
IF YOU ARE TOLD THAT THE PERSON IS NOT HOME, SCHEDULE A CALL-BACK.
WHEN YOU ARE SPEAKING WITH THE INDIVIDUAL, READ...

Hi, my name is _____ and I am a genetic counseling student from The University of Pittsburgh with the Center for Minority Health. You completed a health risk assessment with us in April at _____. I am working on a project to assess changes in people's physical activity habits. I would like to ask you a couple of brief questions to see if anything has changed since your health risk assessment. It should take about five minutes. Is it okay to proceed with the questions? **YES** **NO**

I will read you a definition of physical activity; please tell me if you are physically active based on the definition.

Definition of Physical Activity: The national recommendation for physical activity is engaging in moderate physical activity (walking briskly, mowing the lawn, dancing, bicycling) for 30 minutes a day 5 or more days a week OR engaging in vigorous physical activity (jogging, high-impact aerobics, swimming) for 20-30 minutes a day 3 or more days a week.

Based on that definition, are you physically active?

1 Yes

2 No

1) **(If the person says yes to #1)** Would you say:

1 Yes, I have been for more than 6 months

2 Yes, I have been for less than 6 months

- 2) **(If the person says no to #1)** Would you say:
- 3 No, but I am planning on starting in the next 30 days
 - 4 No, but I am thinking about starting in the next 6 months
 - 5 No, and I don't plan to start in the next 6 months
- 3) **(If the person says no to #1)** Have you increased your physical activity since doing your health risk assessment, but not enough to fit the definition?
- 1 Yes
 - 2 No
- 4) What kind of physical activity do you engage in?
- 1 Walking
 - 2 Jogging
 - 3 Aerobics
 - 4 Bicycling
 - 5 Housework/yardwork
 - 6 Swimming
 - 7 Other _____
 - 8 None

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